ISSN 2458-8865 E-ISSN 2459-1505
www.fppc.com.tr
Family Practice & Palliative Care

Research Article

The relationships between health anxiety and intolerance of uncertainty with quality of life in caregivers of cancer patients

Kanser hastalarına bakım verenlerde sağlık anksiyetesi ve belirsizliğe tahammülsüzlük ile yaşam kalitesi arasındaki ilişkiler

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Abstract

Introduction: A cancer diagnosis is often met with fear and distress in the patient and their family. Cancer also presents many psychosocial challenges for the patient and family caregiver. We aimed to investigate the relationships between health anxiety and intolerance of uncertainty regarding the quality of life in caregivers of cancer patients.

Methods: A total of 83 cancer patients' caregivers were included in the study. A sociodemographic information form, Health Anxiety Scale (HAS), Quality of Life Scale – Family Version (QoL-FV), and Intolerance of Uncertainty Scale (IUS-12), were given to participants to respond. Correlations between the study scale and sub-scale scores were evaluated. Two groups were formed as those with HAS scores greater than and less than the median. It was evaluated whether these groups differed in terms of IUS-12, QoL-FV-Total and QoL-FV subscale scores.

Results: Median (IQR) scores of HAS, QoL-FV-Total and IUS-12 were 18.0 (10.0-25.0), 173.0 (145.0-206.0), and 29.0 (23.0-42.0), respectively. There was a significant positive correlation (r=0.469, p<0.001) between HAS scores and IUS-12 scores and a significant negative correlation (r=-0.328, p=0.002) between QoL-FV-Total scores. There was no significant correlation (r=-0.084, p=0.452) between QoL-FV-Total and IUS-12 scores. The IUS-12 score (median (IQR); 24.0 (20.0-27.0) vs 39.5 (31.5-45.0), p<0.001) was significantly lower and the QoL-FV-total score (median (IQR); 206.0 (157.5-263.5) vs 157.5 (142.25-176.0), p<0.001) and QoL-FV subscale scores were significantly higher in the HAS-low group than in the HAS-high group.

Conclusions: Health anxiety may be one of the negative factors for quality of life in caregivers of cancer patients. More research is needed to explore the factors that predict and protect against health anxiety, which is thought to affect the quality of life of caregivers of cancer patients. Also, psychological intervention studies aiming at the relationship between health anxiety and the quality of life in caregivers of cancer patients are needed.

Keywords: Caregivers, Uncertainty, Health Behavior, Anxiety, Quality of Life

Öz

Giriş: Kanser tanısı, hasta ve ailesinde sıklıkla korku ve sıkıntı ile karşılanır. Kanser ayrıca hasta ve bakım veren için birçok psiko-sosyal zorlanmayı da beraberinde getirir. Kanser hastalarının bakım verenlerinde sağlık anksiyetesi ve belirsizliğe tahammülsüzlük ile yaşam kalitesi arasındaki ilişkileri araştırmayı amaçladık.

Yöntem: Çalışmaya toplam 83 kanser hastasının bakım vereni dahil edildi. Katılımcılara yanıt vermeleri için sosyodemografik bilgi formu, Sağlık Anksiyete Ölçeği (HAS), Yaşam Kalitesi Ölçeği – Aile Versiyonu (QoL-FV) ve Belirsizliğe Tahammülsüzlük Ölçeği (IUS-12) verildi. Çalışma ölçek ve alt ölçek puanları arasındaki korelasyon değerlendirildi. HAS skoru medyandan büyük ve küçük olanlar şeklinde iki grup oluşturuldu. Bu grupların IUS-12, QoL-FV-Toplam ve QoL-FV alt ölçek puanları açısından farklılıkları olup olmadığı değerlendirildi.

Bulgular: HAS, QoL-FV-Toplam ve IUS-12'nin medyan (IQR) puanları sırasıyla 18,0 (10,0-25,0), 173,0 (145,0-206,0) ve 29,0 (23,0-42,0) idi. HAS puanları ile IUS-12 puanları arasında anlamlı pozitif korelasyon (r=0,469, p<0,001) ve QoL-FV-Toplam puanları arasında anlamlı negatif korelasyon (r=-0,328, p=0,002) vardı. QoL-FV-Toplam ve IUS-12 puanları arasında anlamlı bir ilişki (r=-0,084, p=0,452) yoktu. HAS-düşük grupta HAS-yüksek gruba göre; IUS-12 skoru (medyan (IQR); 24,0 (20,0-27,0) ve 39,5 (31,5-45,0)), p<0,001) anlamlı olarak daha düşük ve QoL-FV-Toplam skoru (medyan (IQR); 206,0 (157,5-) 263,5) ve 157,5 (142,25-176,0), p<0,001) ile QoL-FV alt ölçek puanları anlamlı olarak daha yüksekti.

Sonuç: Sağlık kaygısı kanser hastalarına bakım verenlerde yaşam kalitesini olumsuz etkileyen faktörlerden biri olabilir. Kanser hastalarının bakım verenlerinde yaşam kalitesini etkilediği düşünülen sağlık kaygısını öngören ve bunlara karşı koruyucu faktörleri keşfetmek için daha fazla araştırmaya ihtiyaç vardır. Ayrıca kanser hastalarına bakım verenlerde sağlık kaygısı ile yaşam kalitesi arasındaki ilişkiyi hedefleyen psikolojik müdahale çalışmalarına ihtiyaç vardır.

Anahtar Kelimeler: Bakım verenler, Belirsizlik, Sağlık Davranışı, Kaygı, Yaşam Kalitesi

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doi	https://doi.org/10.22391/fppc.1172873			

Key Points

1. Numerous psychiatric or psychosocial problems can be observed in the primary caregiver relatives of cancer patients.
2. There is a relationship between health anxiety, intolerance of uncertainty and quality of life in caregivers.
3. Individuals with high health anxiety may have worse quality of life.

Introduction

A cancer diagnosis is often met with fear and distress in the patient and their family [1]. Also, cancer causes significant disruption and new challenges for the patient and the family caregiver [2]. Caring for patients with cancer affects a caregiver's physical and social well-being [3]. Caregiver family members experience increased severity of depression, anxiety, psychosomatic symptoms, limitations in roles and activities, the tension in marital relationships and diminished physical health [2].

Confronting a life-threatening illness can lead to some proactive health behaviors such as scheduling regular doctor's visits. However, 'health anxiety', which occurs due to a person's over-interpretation of normal bodily sensations even though he or she has no physical illness, can significantly affect individuals and society [1, 4]. The triggers of health anxiety include experiencing a severe illness, witnessing someone else's illness, or being exposed to a threatening health information [5]. Health anxiety develops when individuals catastrophically misinterpret bodily sensations as symptoms of severe illness and engage in anxiety-reducing behaviors, such as excessive reassurance-seeking that reinforce maladaptive disease beliefs and perpetuate health anxiety [5, 6]. Individuals with severely ill parents have significantly higher self-reported health anxiety than individuals with healthy parents [7].

A cancer diagnosis triggers the thoughts of death and disability, initiating a process of uncertainty and many people fear cancer more than any other disease [8]. Facing a health threat, such as an increased risk of cancer, can cause a condition known as intolerance of uncertainty, which brings along anxiety and worry [8]. Intolerance of uncertainty is a tendency to react negatively to an uncertain event or situation, regardless of its probability of occurrence and associated consequences [8]. Intolerance of uncertainty is positively associated with negative mood states such as anxiety, worry and depression in both healthy samples and cancer patients [9].

In this study, we aimed to investigate the relationships between health anxiety and intolerance of uncertainty with the quality of life of the caregivers of cancer patients. Demonstrating such an effect will assist in the early identification of at-risk groups and timely interventions.

Methods

Study design

This study is a cross-sectional observational descriptive study conducted in the outpatient treatment unit of the medical oncology department of Dr Abdurrahman Yurtaslan Ankara Oncology Training and Research Hospital, a tertiary referral center. The data was collected between March 2021 and December 2021 after the local ethics committee's approval.

Study population

The companions of patients diagnosed with cancer and receiving outpatient treatment in the medical oncology clinic were included in the study. All participants were literate, over 18 years of age, and had no physical or mental disability. Participants with a known cancer diagnosis (current or past) or a history of psychiatric treatment (i.e. current or past treatments for depression, anxiety or psychotic disorder) were excluded from the study. Participants with severe and uncontrolled comorbidities (i.e. heart failure, chronic obstructive pulmonary disease, neurological disease, liver failure or kidney failure) were excluded. A sociodemographic information form, Quality Of Life Scale – Family Version (QoL-FV), Health Anxiety Scale (HAS), and Intolerance of Uncertainty Scale (IUS-12), were given to participants to respond. Eighty-three participants were asked to complete the study scales in printed form.

Instruments

Sociodemographic Information Form

A constructed demographic information form included questions about age, marital status (single or married), number of children, comorbidities (i.e. diseases such as hypertension, diabetes mellitus, osteoarthritis, migraine), educational degree (primary / secondary / high school or university), income level (what patients report as very low, low, moderate or high, in their own opinion), employment status, degree of intimacy with the patient, and how many hours per day on average the patient is cared for.

Health Anxiety Scale (HAS)

The Health Anxiety Scale is a self-report scale consisting of 18 items. The 14 items of the scale consist of statements containing quartet answers questioning the mental state of individuals. The remaining four questions are asked about the presumed serious illness of the individuals. The scale scoring is between 0-3 for each item and the total score of the scale consists of the arithmetic sum of each item. Scores above the median indicate a high level of anxiety, and scores below the median indicate a low level of anxiety [4].

Quality Of Life Scale – Family Version (QoL-FV)

Quality Of Life Scale – Family Version (QoL-FV) adopted to assess the quality of life of family members of cancer patients consisting of 37 items. QoL-FV consists of four sub-dimensions: Physical health status, Psychological health status, Social Anxiety and Spiritual well-being. The questions on the scale are scored between 0 and 10 points, with "10" representing the best and "0" the worst. The scale is interpreted on the total and sub-dimension scores, and a high score indicates a high quality of life. Okcin demonstrated the validity and reliability of the Turkish version of the scale [10].

Intolerance of Uncertainty Scale (IUS-12)

It is a five-point Likert-type self-report scale consisting of 12 items in total. The scale can score between 12 and 60 in total. Rising scores indicate a high level of intolerance to uncertainty. The validity and reliability of the Turkish version of the scale were revealed by Saricam et al [11].

Ethical Approval, informed consent, and permissions

Approval was obtained from the local ethics committee (UHS Dr. Abdurrahman Yurtaslan Ankara Oncology Training and Research Hospital Clinical Research Ethics Committee, Approval Date: 10/02/2021, Document No: 2021-02/999). All participants had signed an informed consent form before the enrollment in the study.

Statistical analysis

Statistical analysis was performed using SPSS software (SPSS for Windows, version 24.0., SPSS Inc., Chicago, USA). The nonparametric data were presented as median (interquartile range-IQR), and categorical data were presented as frequency (percentage). The nonparametric correlations were compared using Spearman's rho. The two groups were created as patients with a HAS score greater than or less than the median. Study scale scores of the groups were compared using the Mann-Whitney U test. All statistical tests were two-sided, and P-values of <0.05 were considered statistically significant.

Results

Eighty-three caregivers accompanying the patient diagnosed with cancer and receiving outpatient treatment were included. Median age of the participants was 42.0 (IQR35.0-51.0) years. Most of the participants (n=45, 54.2%) were male. The ratios of educational degree of primary/secondary school and high school/university were 37.4% (n=31) and 62.6% (n=52). Most of the participants (n=64, 77.1%) were married. Income status determined by the individuals according to their own statements was very low/low and moderate/high for 23(27.7%) and 60 (72.2%) participants. Of the participants, 35 (42.2%), 35 (42.2%), 10 (12%) and 3 (3.6%) were spouses, parents, siblings and children of the patients, respectively. Most participants lived in the same house as the patient (n=65, 78.3%). 48.2% (n=40) of the participants were caring for their patients for 1-12 hours a day and 51.8% (n=43) for 13-24 hours. Median (IQR) scores of HAS, QoL-FV-Total and IUS-12 were 18.0 (10.0-25.0), 173.0 (145.0-206.0), and 29.0 (23.0-42.0), respectively. The main characteristics and median study scale scores of the participants are shown in table 1.

Spearman's rho analysis revealed a significant positive correlation (r=0.469, p<0.001) between HAS scores and IUS-12 scores and a significant negative correlation (r=-0.328, p=0.002) between QoL-FV-Total scores. There was no significant correlation (r=-0.084, p=0.452) between QoL-FV-Total and IUS-12 scores. The results of correlation analysis between study scales and subscales are shown in Table 2.

Table 1. Main participants' characteristics

		n	%
Age§		42	35 - 51
Gender			
	Male	45	54.2
	Female	38	45.8
Employment status			
	Employed	43	51.8
	Unemployed	40	48.2
Marital status			
	Single	19	22.9
	Married	64	77.1
Educational status			
	Primary and secondary school	31	37.4
	High school / University	52	62.6
Co-morbidity			
	No	59	71.1
	Yes	24	28.9
Income status			
	Very low - Low	23	27.7
	Moderate - High	60	72.3
Kinship status			
	Spouse	35	42.2
	Parent	35	42.2
	Sibling	10	12.0
	Child	3	3.6
Living with the patient			
	No	18	21.7
	Yes	65	78.3
HAS§		18	10 - 25
QoL-FV. Total§		173	145 - 206
	QoL-FV.1§	27	20 – 36
	QoL-FV.2§	60	42 – 80
	QoL-FV.3§	43	32 – 61
	QoL-FV.4§	45	38 – 51
IUS-12§		29	23 - 42

§ Given as median (range IQR); HAS, Health Anxiety Scale; QoL-FV, Quality of Life Scale – Family Version; IUS-12, Intolerance of Uncertainty Scale

Table 2. Correlation analysis results including study scale total scores and subscale scores.

	HAS	IUS-12	QoL-FV.1	QoL-FV.2	QoL-FV.3	QoL-FV.4	QoL-FV. Total
HAS	1						
IUS-12	0.469**	1					
QoL-FV.1	-0.243*	-0.128	1				
QoL-FV.2	-0.310**	-0.030	0.490**	1			
QoL-FV.3	-0.278*	-0.090	0.479**	0.610**	1		
QoL-FV.4	-0.029	-0.054	0.385**	0.315**	0.291**	1	
QoL-FV. Total	-0.328**	-0.084	0.704**	0.844**	0.802**	0.544**	1

HAS, Health Anxiety Scale; IUS-12, Intolerance of Uncertainty Scale; QoL-FV, Quality of Life Scale – Family Version, * p <0.05; ** p <0.01

The IUS-12 score was significantly lower in the HAS-low group than in the HAS-high group (median (IQR); 24.0 (20.0-27.0) vs 39.5 (31.5-45.0), p<0.001). The QoL-FV-total score (median (IQR); 206.0 (157.5-263.5) vs 157.5 (142.25-176.0), p<0.001) and QoL-FV subscale scores were significantly higher in the HAS-low group than in the HAS-high group. The comparative evaluation results of the study scale scores of the HAS-low and HAS-high groups are shown in Table 3.

Table 3. The comparison of study scale scores of participants whose health anxiety scale scores were less than median (HAS low) and greater (HAS high)

		HAS low Median (range)	HAS high Median (range)	p
IUS-12		24.0 (20.0-27.0)	39.5 (31.5-45.0)	**0.001**
QoL-FV. Total		206.0 (157.5-263.5)	157.5 (142.25-176.0)	**0.001**
	QoL-FV.1	33.0 (20.5-42.5)	23.5 (20.0-30.0)	**0.002**
	QoL-FV.2	80.0 (45.0-104.5)	52.0 (42.0-62.0)	**0.002**
	QoL-FV.3	60.0 (37.0-69.0)	39.0 (29.75-44.0)	**0.001**
	QoL-FV.4	48.0 (39.5-55.0)	42.5 (35.0-49.25)	**0.040**

HAS, Health Anxiety Scale; IUS-12, Intolerance of Uncertainty Scale; QoL-FV, Quality of Life Scale – Family Version

Discussion

In this study, we aimed to reveal the relationships between health anxiety and intolerance of uncertainty with the quality of life of caregivers of cancer patients**.** We have found a significant negative correlation between QoL-FV-Total and HAS scores. There was no significant correlation between QoL-FV-Total and IUS-12 scores. Also, we have found a significant positive correlation between HAS and IUS-12 scores. To our best knowledge, there is no literature data concerning the relationships between health anxiety and intolerance of uncertainty with the quality of life of caregivers of cancer patients. Our study is the first study on this issue and contributes literature knowledge.

Research shows that caregivers have significantly more anxiety than the average population and that patients' illnesses can severely impact their caregivers' health and quality of life [12]. Negative and positive caregivers' experiences about caregiving and their primary physical and emotional states affect their ability to care for cancer patients [12]. There is no study in the literature examining the relationship between quality of life and health anxiety in caregivers of cancer patients. However, as a sub-dimension of the scales assessing the quality of life in caregivers of cancer patients, the findings regarding the deterioration of physical health in these individuals draw attention [13, 14]. In our study, it has been found that the lowest scores in the physical health sub-dimension of the QoL-FV scale were found in line with the literature [13, 14]. Rivera et al. reported that caregivers of cancer patients often felt tired, had challenging sleep, lost appetite, had cold, sadness, and guilt due to illness, and their interest in activities they previously enjoyed decreased [13]. Some physical health problems such as weight loss, insomnia, backache, and headache have been observed in mothers caring for a child with cancer [14]. Oberst et al. found that 75% of the caregivers had physical problems before their patients were discharged, and about half of these problems persisted after discharge [15]. In a study by Ferrell et al., family members who care for ovarian cancer patients stated that they felt fatigued, and many health problems emerged from the onset of the disease [16].

Previous studies show that the caregiving process harms the person's psychosocial, mental, physical, spiritual, and emotional health and significantly reduces the person's quality of life [17, 18]. The use of quality-of-life assessment increases the likelihood that health care professionals will identify caregivers' problem areas and unmet needs and monitor outcomes in clinical practice [19]. Determining the factors affecting the quality of life in caregivers and developing solutions for those factors is essential for the health of both the caregiver and the cancer patient. In our study, the scores of family members on the quality-of-life scale were relatively low.

Cancer is a condition that causes more fear than any other disease [20]. The prevalence of cancer fear in the population may have implications for quality of life [20]. In health anxiety, extreme anxiety focuses on one's present and future health. It has been suggested that triggers for health anxiety include experiencing a severe illness such as cancer, witnessing someone else's illness and treatment process, such as a relative or friend, or being exposed to a threatening health information [6]. Few studies have assessed the assumption that witnessing another person's illness precipitates health anxiety [21]. Evidence suggests that a loved one experiencing cancer can precipitate health anxiety [1]. However, it is unclear whether their anxiety is attributed to having genetic risk factors for these diseases or whether the participants' indirect experience of illness preceded their health concerns [1]. Being genetically related to a cancer patient can trigger thoughts about one's health [22]. Children who have observed their parents' long and difficult battle with cancer have seen an increase in health anxiety due to the belief that medical illnesses are terrible and

resistant to treatment and their misinterpretation of harmless bodily sensations and changes due to such beliefs [7]. However, it has also been suggested that parental illness may lead to more adaptive cognitive processing in children, increase the child's resilience to the real threat of illness, and potentially alert individuals to practical and valuable therapeutic information about a disease they may be at risk of developing [23].

There are very few studies in cancer patients and caregivers regarding intolerance to uncertainty [24], defined as the tendency to react negatively to an uncertain event or situation, independent of its probability of occurrence and associated consequences [25]. There is no study investigating the relationship between intolerance of uncertainty and quality of life in caregivers of cancer patients. In our study, which evaluates this relationship, no correlation is found between intolerance of uncertainty and quality of life in caregivers of cancer patients. In the literature, few studies related to intolerance to uncertainty in cancer patients have attracted attention. Studies show that uncertainty is associated with increased fear of cancer recurrence and decreased quality of life in patients [26]. In our study, a positive correlation is found between intolerance of uncertainty and health anxiety in caregivers of cancer patients. Considering that both situations are reactions to a possible uncertain situation, this result can be expected as an expected result. Studies evaluating the relationship between intolerance of uncertainty and quality of life and health anxiety will provide new information in this area.
Our findings point to further studies on the role of the effect of health anxiety and intolerance of uncertainty on the quality of life of caregivers of cancer patients**.**

Limitations

The cross-sectional nature of this descriptive study limits its ability to understand change over time and prevents causal inferences. Factors such as the patients' symptoms, the stage of the disease, caregiving time, and the patients' performance status may affect the quality of life of caregivers of cancer patients and health anxiety. Other sociodemographic variables that were not analyzed, such as gender, education level, age, or social support network, may also be associated with the quality of life and health anxiety. Also, health concerns may differ among participants with indirect cancer experiences, depending on whether they have been recently diagnosed, treated, or in remission or are at high risk for developing cancer, such as genetic burden. Longitudinal studies are needed to examine the evolution of health anxiety over time and to determine the temporal expansion of these factors.

Despite the current study's limitations, our findings contribute significantly to the knowledge of the literature as being the first study to investigate the effect of health anxiety and intolerance of uncertainty on the quality of life of caregivers of cancer patients**.** This study can also be a starting point for new prospective, longitudinally, and multi-dimensional designed studies on the same aspect of caregivers' quality of life, health anxiety, and intolerance of uncertainty considering comprehensive factors (i.e. factors related to caregivers, patients, and diseases).

Conclusion

This study is the first to examine the effects of health anxiety and intolerance to uncertainty on the quality of life in caregivers of cancer patients and to find a significant correlation between health anxiety and quality of life. Evaluation of health anxiety and timely intervention can help improve the quality of life of caregivers of cancer patients. The patient and caregiver spend time together, predominantly for a long time and most of the day. Each characteristic of the caregiver will affect the care given. It is essential to know the characteristics of caregivers, identify the group that at risk of difficulties, and create support groups according to these characteristics to improve the services provided by health institutions. Early screening of conditions such as health anxiety, which may adversely affect the quality of life by putting caregivers at a specific risk in terms of developing symptoms and problems, identifying caregivers at risk, and timely intervention are essential in preventing the development of psychopathology. Our study and future studies can inform the development of evidence-based ways to refer cancer caregivers to psycho-oncology services.

Conflict of interest: None.

	Author Contributions	**Author Initials**
SCD	Study Conception and Design	PE, AI
AD	Acquisition of Data	AI
AID	Analysis and Interpretation of Data	PE, AI
DM	Drafting of Manuscript	PE
CR	Critical Revision	PE, AI

Financial support: None
Acknowledgments: None
Prior publication: None

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